Refer to: California's Natural Death Act—Medical Staff Conference, University of California, San Francisco. West J Med 128:318-330, Apr 1978

California's Natural Death Act

These discussions are selected from the weekly staff conferences in the Department of Medicine, University of California, San Francisco. This month's Conference is taken from a transcription of a Medical Grand Rounds sponsored by the Dean's Forum Committee and held January 19, 1977. The discussions are followed by the results of a survey conducted among physicians. Requests for reprints should be sent to the Department of Medicine, University of California, San Francisco, CA 94143.

DR. SMITH:* *A group of concerned faculty members from this campus under the heading of the Dean's Forum Committee sponsors this Grand Rounds. The purpose of the committee is "to examine the issues which influence the proper clinical management of patients, particularly those issues wherein physicians' perceptions of the nature of the illness have an effect, where the state of knowledge is such that the management is in experimental phase, where interdisciplinary modes of management may either support, or interfere with, appropriate outcome; and, where ethical considerations and the participation of the patient, in the decision concerning his or her management, are unclear and need definition."*

It has been the privilege of the Department of Medicine to turn over Medical Grand Rounds to the Dean's Forum on two previous occasions. We do so again this morning. I would now like to introduce Dean Julius R. Krevans who will introduce this forum.

DR. KREVANS:† Thank you, Dr. Smith. Our society extends to physicians an awesome privilege, and awesome authority, in the relationships of physicians to the problems which patients bring to them. With that privilege, and authority, goes a very substantial and important responsibility.

In turn, institutions such as ours, which are given the unique charge for education of physicians, have to examine how we structure our education to illustrate that responsibility and privilege are given to physicians dealing with patients' problems. I do not need to defend the rationale whereby we insist that physicians understand the complex interrelationships between the basic sciences and the clinical sciences. Helping a patient is more than understanding science and, in the art of medicine, we have the responsibility to examine these other issues.

We talk about the need for humanity in medicine. Several years ago we had a long seminar on "Humanity in Medicine" on this campus. I attended the seminar and listened to the discussion by a group of sociologists, economists, anthropologists and a variety of other "ists" who had in common only one thing: none of them had ever touched a patient. I became concerned that they were missing a very important point. Toward the end of the conference, the chairman called on me and asked if I had learned anything. I said I had indeed and, as a matter of fact, learned so much that I had evolved instantly a new theory on humanity in medicine which I entitled "The James Barrie Theory of Humanity in Medicine." It goes like this: humanity in medicine is controlled by a group of angels, and every time someone says "provider," instead of physician or nurse, one of those angels dies; and every

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time someone says "consumer," instead of patient or person, another angel dies; and, when all the angels are dead, there will be no humanity left in medicine.

The forum we are having this morning deals with one of these difficult issues. I have asked Dr. Harrison Sadler to conduct the program.

DR. SADLER:* *Thank you, Dr. Krevans. I shall introduce the members of the panel as we go along in order to match the name with the person. The author of the Natural Death Act legislation, Mr. Barry Keene, is here and I am sure before you leave today you can have your questions answered.*

You will see this is a limited bill, applicable only to terminal illnesses and the use of life-support systems. In essence, it is a piece of legislation that encourages a patient to participate in his or her own terminal care and gives legal sanction to his, or her, directive to the attending physician to carry that out.

You physicians will experience a general restlessness: is this not an intrusion on medical care; will it not generate more problems? Perhaps the legislation was necessary as a consequence of increasing feelings of clinical helplessness as physicians experienced coercion, on the one hand, by the presence of scientific and medical technology which was able to sustain life; and, on the other hand, by the fear of suit for malpractice.

I feel, beneath all this, that there is a strange morality which is becoming increasingly popular. It is the assumption that is characterized by the words "why not," and the phrase "if we have it, let's use it." The assumption can be heard daily from patients, from the clinical team, from hospital administrators and, indeed, even from insurance carriers. This bill, then, underscores the role of technology as another clinical option, not a necessity. Primarily it encourages negotiation between physicians and patients over its use. Personally I feel "negotiation" is the key word in what we are discussing today. I am sure we shall have a chance to debate that as the year goes along because we are discovering in another research project called the quality of life in chronic illnesses that this word—negotiation—is the key one in the definition of the quality of life for it involves on the one hand, full information and on the other hand, increasing freedom. This bill is one that tends to enhance the dignity of all, and I think you will see this as the forum goes along today.

One message needs to be underscored for the attending physicians and the house staff: the information to the patient and the negotiations about his, or her, participation need to be considered before *one enters what I call the clinical cul-de-sac. To initiate the use of life-support systems before negotiation with the patient takes us into a clinical cul-de-sac with few options to help us out again. With this in mind, I call your attention to Figure 1, which gives guidelines about the Natural Death Act for patients.*

First, I will call on Dr. Benson Roe. Dr. Roe is a Professor of Surgery whose specialty is cardiovascular procedures.

DR. ROE:† Thank you, Dr. Sadler. The subject of our forum this morning is a direct product of the tremendous advances in medical technology that have taken place over the past several years. It seems that the immense benefits derived from our expanded capabilities are accompanied by some serious problems.

My familiarity with this subject derives from my involvement in the pioneering days of open-heart surgery which were fraught with tragedies and disappointments, as we learned to understand and master the complexities of this particular specialty. Much of modern technology evolved from such experience and, perhaps, that is why I am here today. We learned, at least, to be persistent and not to give up hope.

We once saw patients who did not wake up after a successful intracardiac repair, presumably because of air embolus, and who would remain in coma on respiratory support for very long periods. Often we thought these were terminal cases, yet some of the patients would recover.

How long can we hold on to some hope for recovery? How can we justify continuing the anguish, and the false hope, for the family? How much of our resources, and manpower, can be appropriately diverted to this demoralizing exercise in futility, particularly when it is inevitably at the expense of our other patients? These questions have no undisputed answers and, yet, there clearly comes a time when a situation is futile and further efforts are unjustified. Until now we have had no way of dealing with the problem.

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CALIFORNIA NATURAL DEATH ACT

Guidelines and Directive

These guidelines have been drafted by an ad hoc committee convened at the request of Assemblyman Barry Keene, composed of the Los Angeles County Bar Association's Committee on Bioethics, California Hospital Association Legal Counsel, California Medical Association Legal Counsel and representatives of the Office of Assemblyman Keene.

GUIDELINES FOR SIGNERS

The DIRECTIVE allows you to instruct your doctor not to use artificial methods to extend the natural process of dying.

Before signing the DIRECTIVE, you may ask advice from anyone you wish, but you do not have to see a lawyer or have the DIRECTIVE certified by a notary public.

If you sign the DIRECTIVE, talk it over with your doctor and ask that it be made part of your medical record.

The DIRECTIVE must be WITNESSED by two adults who (1) are not related to you by blood or marriage, (2) are not mentioned in your will, and (3) would have no claim on your estate.

The DIRECTIVE may NOT be witnessed by your doctor or by anyone working for your doctor. If you are in a HOSPITAL at the time you sign the DIRECTIVE, none of its employees may be a witness. If you are in a SKILLED NURSING FACILITY, one of your two witnesses MUST be a "patient advocate" or "ombudsman" designated by the State Department of Aging.

You may sign a DIRECTIVE TO PHYSICIANS if you are at least 18 years old and of sound mind, acting of your own free will in the presence of two qualified witnesses.

No one may force you to sign the DIRECTIVE. No one may deny you insurance or health care services because you have chosen **not** to sign it. If you **do** sign the DIRECTIVE, it will not affect your insurance or any other rights you may have to accept or reject medical treatment.

Your doctor is bound by the DIRECTIVE only (1) if he/she is satisfied that your DIRECTIVE is valid, (2) if another doctor has certified your condition as terminal, and (3) at least 14 days have gone by since you were informed of your condition.

If you sign a DIRECTIVE while in good health, your doctor may respect your wishes but is not bound by the DIRECTIVE.

The DIRECTIVE is valid for a period of five years, at which time you may sign a new one.

The DIRECTIVE is not valid during pregnancy.

You may revoke the DIRECTIVE at any time, even in the final stages of a terminal illness, by (1) destroying it, (2) signing and dating a written statement, or (3) by informing your doctor. No matter how you revoke the DIRECTIVE, be sure your doctor is told of your decision.

Figure 1.—Guidelines developed for signers of California's Natural Death Act.

I believe, however, that the time has come for us to acknowledge and define our limitations. When our obligation to do everything possible for an individual patient is in conflict with our overall responsibilites, then we are in trouble and we need help.

The Natural Death Act is a very important step in that direction and, most significantly, it acknowledges public and legal involvement in a problem which, until now, the physician has had to shoulder alone and which many times has made him behave senselessly, inhumanely or, surreptitiously, illegally. I think it is not unreasonable to suppose, or to assume, that further advances of expensive medical technology will soon reach the stage where even our affluent society will no longer be able to underwrite a blank check for health care if every hospital death is to be accompanied by a $100,000 effort to sustain life. The Keene Bill is a landmark beginning—a start at finding solutions for complex, knotty future questions concerning the physician's role in the dying process.

DR. SADLER: *Mr. Barry Keene represents the north coast counties in the California Assembly. He is a lawyer by profession and the author of this legislation. Thank you very much for coming, Mr. Keene.*

MR. KEENE:* Let me begin by issuing a disclaimer concerning my role here today. I appear before you not as an expert but more as an historian. I have no true expertise in medicine, although I learn more about health care daily, and I am certainly responsible for policy decisions in that field at the legislative level. I am not an expert on death and dying, although I have had occasion to resort to much of the literature. I am certainly not, nor would I ever presume to be, an expert on ethical questions, having learned what I have about human nature in the course of the legislative process and all of its complexities. What I am able to do is relate to you the personal considerations and the group dynamics that led to the passage of the Natural Death Act.

The bill is not well-founded in empirical data. It is largely the product of some personal experiences, not only mine but also those of people in the medical field, in the ministry and in the legislature—all of whom have had some intimate acquaintance with the process of dying. We did interview physicians; we did contact tertiary care centers; we did talk to nurses. We did gain insights from them. We did also speak with some terminally ill people and we gained insights from them as well.

Is there a need for the bill? Is legislative intrusion, or intervention, justified in an area such as this? One of the things we determined is that the question produces a great deal of anxiety in the course of the relationship among physicians, hospitals, nurses, clergy and relatives and the terminally ill patient. It produces anxiety for all of them, even the people who say everything is all right but who do not want to talk about it; those who do not want to tell you what happens, but who assure you everything is being taken care of. The doctors, in many instances, are placed in the position of making a decision which is not only a medical judgment, for which they are trained, but also an ethical judgment. That produces anxiety.

Physicians, we are told, will have a better feeling for and insight into this attitude. Physicians are trained to keep people alive. Perhaps this spills over into situations even when they are not able to do so. As for a terminally ill patient, he or she often feels in a kind of custodial situation —that is, under the control of forces which are beyond one's own right to self-determination. This consideration is an important feature of the bill.

As you doctors well know, many of my colleagues in the legislature are attorneys and, therefore, are concerned with constitutional rights and with individual liberties. There are a cluster of individual rights which we felt were being denied to terminally ill patients; for example, due process before having one's body placed in a custodial situation where others are making the decisions. One of the most intimate and potentially offensive acts is invasion of the human body itself without that decision having been made, or necessarily assented to, by the terminally ill person. Finally, one must consider the whole question of individual self-determination; why should self-determination be denied to people who are terminally ill?

The opponents of the measure felt it was a foot-in-the-door leading to euthanasia: soon we were going to be "killing" other categories of people—the retarded and the elderly, for example. We had two responses. The first was that this differs from the offensive aspects of euthanasia. It is not someone else deciding when a person ought to die, except with reference to objective

*Honorable Barry Keene, Chairman, Assembly Committee on Health, State of California.

factors. The terminally ill patient, in a prospective way, makes the decision. The second aspect that distinguishes this from euthanasia is that we are not talking about a category of people and determining *whether* they ought to die, but *how* they ought to die. Those most affected by the prospect of dying ought to determine how their final days are to be spent.

The American Medical Association misunderstood the bill. They, and some other opponents of the bill, felt this would be the exclusive mode of determining when a terminally ill patient would have life-support systems removed. That is not the case. This is a parallel procedure. The measure specifically states that it does not affect the law with reference to the removal of life-support systems in situations where directives have not been prepared. The California Medical Association studied it much more carefully; therefore, they took a different position on the measure.

We also had to deal with political problems. We were presented with ideas from the opposition, some of which were good ideas, making it necessary to move more slowly than originally anticipated. We did not want to get into a lot of collateral ethical issues. We could not handle all of those at the same time. We wanted the legislature to concentrate on the key issue—the rights of the terminally ill. We did adopt a two-tier procedure. First, if a person is not terminally ill at the time he or she makes out the declaration, the doctor may (and, based on samples we have taken, probably would) effectuate the directive. The notion was that a person not terminally ill would not be capable of making as sober a judgment on a question like this but, at least, the doctor involved would have a directive providing some orientation about the earlier feelings of the person who becomes terminally ill. They were prevented from doing so by fear of liability and by pressures from relatives who are close by. As for a terminally ill person who wishes to make out a directive, it was felt that at the time of the diagnosis he or she is in no emotional state to prepare a directive of this kind, such that it should be effectuated without question by the physician. So, a 14-day period was allowed to let the patient consider the situation and to determine whether he or she really wanted to go ahead. At that point, we felt that so serious and sober a consideration had been given to the question that the doctor ought to be required to effectuate it. That is provided in the bill.

We provided formalities in the preparation, and signing, of the declaration that are very similar to those of a will. We did not call it a will because that causes legal confusion; wills by definition are effectuated after a person has died. We provided for revocation, an act which does not require the same degree of formality as the preparation of the document. It is quite easy to revoke the document but the revocation must be communicated before anyone is held responsible for knowledge that the directive is in fact revoked. The clause that the directive could not be effectuated if the signator were pregnant was one of the collateral ethical issues we simply did not want to get involved in. It would have brought the whole question of abortion into the legislative dialogue. We did not want beneficiaries, and others who might stand to gain some advantages, to be witnesses to the directive. There was some feeling that people in nursing homes, because they were unaccustomed to making independent decisions by virtue of their situation, ought to be further protected. Therefore, we provided for one of the witnesses in the bill to be a state-authorized ombudsman, or representative, for these people. For people who prepared one of these directives at a time when they were not terminally ill, we felt there ought to be a five-year gap. They would have to sign one of these directives again after five years to make sure the judgment they originally made was one about which they were serious, and that they had not changed their minds.

To sum up, we felt there were people who in the event of terminal illness would not want to spend their final days tyrannized by machines when the only purpose (and this is the key language) of those machines is to postpone the moment of death artificially where no cure is possible and where death is, in any event, imminent. Some of the critics have asked what we mean by imminent. How can we be sure the diagnosis is one of terminal illness? The answer is that we could not pass bills that provide, with a great deal of specificity, what really amounts to a medical judgment. There is a certain amount of subjectivity in every bill we write. We prepare legislative policy and, to some extent, we leave the people affected by that policy in an uncomfortable position of filling out a lot of the details. We probably have made mistakes in some of the provisions of this legislation. There will be better ways of handling certain of the procedures, different ways of handling them which are more conducive to

our purposes. These better approaches will be a product of the kind of discussion you are having here today. The bill essentially substitutes, in exchange for the ad hoc kind of decision-making which exists today, a prospective decision by the patient in the form of a directive to the physician that meaningless life-support systems be removed if death is imminent and, of course, provides a freedom from liability for the physician who does effectuate one of these directives.

DR. SADLER: *Thank you, Assemblyman Keene. I think you can sense why it is necessary to have someone who is conversant with ethics on every medical campus. May I present Dr. Albert Jonsen, Associate Professor of Bioethics.*

DR. JONSEN:* What are the ethical issues raised by the Natural Death Act? I wish to state what I see as the ethical import of the Act itself; then, I shall venture some predictions about its ethical implications.

The import of the Act itself might be summed up in four propositions:

1. It is a statement of an already well-recognized legal right; namely, the legal right of persons to refuse medical treatment. This has been made clear by American courts during the last half century with certain specific qualifications, such as there being no harmful consequences to others as a result of the refusal. The Act not only makes this statement but also applies it to a situation not made entirely clear by earlier precedents; namely, the legal force of a directive given in anticipation of the event; that is, the critical period when death is imminent and the patient unable to express his or her will. It also seeks to clarify another cloudy area: the matter of the criminal or civil liability of those who honor such a directive although, despite the theoretical possibility of indictment and conviction, only a handful of cases has been reported and few have ever come to trial. No conviction has ever been handed down and, as Curran and Shapiro write in their *Law, Medicine and Forensic Science,* "There is no American appellate court decision involving euthanasia and a physician." Still, this specter is banished (for at least one sort of case) and reasonable personal and clinical decisions are no longer menaced.

2. The Act is an acknowledgment of the moral autonomy of persons to control their own lives at a time when their actual ability to exercise such autonomy is most compromised. As such, it is a manifestation of the moral principle of respect. While the question of suicide and its abetment may be raised, I do not think that in general any reasonable case can be made that the moral definition of suicide is applicable when medical treatment, which is essentially incapable of restoring function, is refused. This legislation makes it clear that legally such an act cannot be defined as suicide.

3. The Act is a reaffirmation of the long tradition in medical care that the determination of the inefficacy of treatment lies in the hands of the physician and the determination of the undesirability of treatment lies with the patient. Sensitive physicians have always known decisions about dying, difficult as they may be, are in some very important sense mutual and reciprocal decisions. This act confirms such awareness.

4. The Act is a warning that the high degree of organization and efficiency demanded by current technology should not be allowed to overwhelm the humanity and the needs of the dying patient. It inserts into the technological setting an imperative to respect the most humane and tragic of decisions, the decision to no longer live.

I shall venture several predictions about the implications of the Act:

1. Little will change in the actual course of clinical practice. Physicians must still diagnose terminal illness and determine terminal condition, with all the uncertainty, anguish and occasional error involved in those acts. The evaluation of patients will require time, repeated interventions, tentative efforts before the definitive judgment. Even that judgment will be definitive more because of instinct and experience than evidence.

2. The Act will not open the floodgates to a cascade of euthanasia or to an orgy of mercy killing. On the other hand, one adverse side effect may be to make physicians, who do not understand the Act or its intent, even more reluctant to follow good clinical judgment and discontinue treatment for those who do not present the requisite directive. This would be a most unfortunate misunderstanding.

3. The Act will relieve much of the moral anxiety, if not the psychological anxiety, when the directive is mandatory in the case of the "qualified patient" and when family, or other interested parties, are in distressed perplexity or urge the physician to continue treatment which

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in his, or her, judgment is of no avail. In such a case good clinical judgment, fortified by the patient's directive, overrides the opinions of others which may be distorted by grief, guilt and sometimes greed.

4. The Act will initiate pressure for more precise, detailed and recorded orders regarding resuscitation of terminally ill patients. This pressure, which has been resisted by many physicians and even by legal advisors, will lead to establishment of categories of patients in intensive care, as has already been done at the Massachusets General Hospital and the Beth Israel Hospital in Boston. The problems attendant on such classifications will have to be faced with care and honesty.

A variety of particular questions of interpretation will arise in the course of practice. Is a patient in renal failure "in a terminal condition" since dialysis can reverse the condition? Is the administration of insulin one of those "life-sustaining procedures" which can be withheld? Is administration of blood to an exsanguinating patient "a mechanical or artificial means"? How is a patient, after there has been a diagnosis of terminal disease—say, glioblastoma—and after having signed a directive, to be treated when brought to the emergency room moribund from barbituate poisoning? Such questions will have to be answered by careful study of the legislative language, by accurate presentation of the circumstances and by common sense. Their interpretation hinges, I believe, on the very important words of the Act, "artificially prolong the moment of *death* . . . where, in the judgment of the attending physician, death is imminent *whether or not* such procedures are utilized."

A final comment. Every effort to modify major social patterns, whether by law, by invention or by ideas, can be seen either in its broad sweep or in its fine details. If the broad sweep is missed and only the fine details picked out, the effort is distorted. If only the broad sweep is noted and the fine details neglected, the effort is empty. It is the duty of the profession to understand the intent of this legislation, recognize the real and imagined problems which inspired it and to come to grips with the many questions of detail, in expression and application, which it represents, thinking them through as they apply to real clinical situations and expressing them in clear and sensitive policy.

DR. SADLER: *Let me invite you to meet a patient whose case illustrates the clinical features of the Natural Death Act. Dr. John Solters, who is a Fellow in Nephrology, will present the overview.*

DR. SOLTERS:* Mr. J is a 49-year-old man in whom end-stage renal disease is secondary to diabetic glomerulosclerosis. Diabetic complications include lower extremity neuropathy but no significant ocular or cardiovascular problems. Mr. J began maintenance hemodialysis at the University of California Renal Center in November 1973. He has had a multitude of vascular access procedures with significant attendant morbidity. A summary of these events is as follows.

The patient began dialysis with a left thigh saphenous vein graft which clotted irreversibly after 4½ months. A silastic cannula was then inserted in his left forearm and functioned well for 14 months until March 1975. At this time a bovine graft was placed in his right forearm. This graft clotted but thrombectomies were done on eight separate occasions and lasted a total of 12 months. Another silastic cannula placed at his left ankle functioned for a few weeks so that, in April 1976, a bovine graft was placed creating a fistula in the patient's right upper arm. This access lasted two months and clotted secondary to infection.

In June 1976 a bovine graft was then placed in the left upper thigh and functioned for only five weeks. An abscess had developed around the graft and a resultant pseudoaneurysm required emergency arteriotomy and graft ligation. Unfortunately, the graft was not removed entirely and draining sinuses persisted for several weeks.

Since February 1976 dialysis has been carried out in the patient reliably via a silastic cannula in his left forearm. He has undergone a revision of the venous limb in April, an arterial revision in June and a second venous revision in August 1976. This access has very low blood flows, but fortunately no high venous resistance when the blood pump is used. The shunt has clotted several times but has been successfully declotted each time. The patient's family administers heparin via a T-piece at home, and the patient is receiving aspirin by mouth.

For the past six months, Mr. J has noted severe functional impairment of his right hand and left foot. He has a foot drop with pronounced wasting, weakness and unobtainable nerve conduction velocities in the leg. Ulnar and median nerve

*John Solters, MD, Fellow in Nephrology, Division of Nephrology, University of California, San Francisco.

damage is documented in his right hand. The patient writes with great difficulty and cannot hold objects for a prolonged period. His gait is hampered by the foot drop; he required crutches and can no longer drive his car. Efforts at physical rehabilitation have not altered his disability.

In November 1976 Mr. J met with Dr. Robert Lim, his surgeon, and discussed the possibilities of further access procedures. Dr. Lim proposed access placement sites in the left upper arm as well as Thomas shunt placement in a thigh. The patient declined any further procedures when he learned that functional impairment of the operated limb was a continued risk. Peritoneal dialysis via a permanent peritoneal catheter at home was offered and declined. The patient's age and diabetes have prevented serious consideration of transplantation.

The patient is well aware that when dialysis can no longer be carried out via his cannula, his death is imminent. In that event, he has left written instructions that no surgical or mechanical means be employed to prolong his life.

Mr. J is married and has four children. His wife sympathizes with his position but feels he should agree to further surgical procedures. Deprived of his customary social outlets, the patient spends his time at home watching television or napping. A recent bout of hepatitis with consequent food and stool precautions has decreased social contacts at home. He currently anticipates thrice weekly dialysis as an opportunity to socialize. Appetite and energy levels had responded to administration of amitriptyline hydrochloride (Elavil®), which was discontinued when the patient reported possible hallucinations.

DR. SADLER: *Mr. J, how does it feel to have all these things going on about you? You realize you are a pioneer because you really signed this bill before Mr. Keene got it through the legislature.*

MR. J: Well, I told the doctor I did not want any more operations because of the way I feel. The doctor actually asked "Do you know what you are saying?" I said "Yes, I do." He said "When this graft in your arm goes out, that's it, because that means death." I asked "What does that mean? Go through another operation, taking a chance that nothing may happen?" I said "I prefer not to have another operation. This may last for ten years and it may last for ten weeks; I do not know. Whatever time it lasts, I'll be satisfied with that—but, no more operations."

DR. SOLTERS: *Mr. J, you first brought this up to me about six months ago, is that right?*

MR. J: About six months.

DR. SOLTERS: *We talked about it then. I assured Mr. J at the time that his body was his own and he could say what was to be done with it. If he did not want any further accesses, it was his decision so long as he was well aware of what the consequences would be.*

Mr. J, it perked along in your head for some time before you actually made the decision. We talked about it in the summertime, and you signed the directive in November.

Ms. Kathleen Lavery is our nurse. Ms. Lavery, can you tell us about some of the conversations you had with Mr. J about this?

MS. LAVERY:* Mr. J expressed to me, after the last surgical complications, that he did not want any more procedures done. I asked him, was he sure? Had he made up his mind this was what he really wanted? I respected him for making the decision, and I relayed this information to the doctor to make sure he understood how Mr. J felt. Then we took it from there, having several meetings with the medical staff and the medical team to make sure Mr. J was aware of the consequences.

DR. SADLER: *As a nurse, did you feel much anguish about this whole procedure?*

MS. LAVERY: Yes, there was much anxiety on my part and on the part of some other staff members. Also, there was frustration and helplessness, not knowing what else to do. In a way I also respected Mr. J's decision to do this because there were really no more alternatives for him, and he would just suffer more.

DR. SADLER: *Ms. Elaine Fripp is the social worker on Mr. J's case. Ms. Fripp, do you have some feelings about it?*

MS. FRIPP:† The extent of social-work intervention in a case such as this largely depends on the institutional setting and the internal climate of that setting. Take, for example, dialysis as a form of treatment. It is not given in isolation. You

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†Elaine Fripp, MPH, Clinical Social Worker, Dialysis Unit, San Francisco General Hospital.

have to think about the effects of this decision on the other patients, the family and the staff; and, as a social worker in this setting, I see my role mainly as maintaining, establishing or reestablishing communication in the patient's network of human relationships. In addition I have been studying the status of "social death," in which patients give up social contact and withdraw into a deep personal enclave. When this happens they are hard to help and often develop increasing medical complications.

DR. SADLER: *I would like to introduce Dr. Hillary Don, director of the Intensive Care Unit, Moffitt Hospital.*

DR. DON:* I am impressed with this patient's personal courage and dignity. I want to turn to a slightly different aspect of the Natural Death Act, that is, its relationship to the Intensive Care Unit and its effects within this hospital.

The Natural Death Act addresses the issue where the indignities and misery sometimes inflicted on patients provide nothing medically necessary or beneficial to that patient. It has always been the patient's right to refuse treatment. It has never been labeled suicide for a patient to refuse treatment and such a decision has been invariably respected by physicians and by the law. This will not be altered by the Natural Death Act.

However, the second category, in which a patient who may or may not have signed a declaration is comatose or cannot make a decision, is one which I want to talk about.

If a patient has signed a declaration before this episode, the physician is bound to use his judgment as to whether to fulfill the directive. This has always been a physician's duty and his responsibility: to make a judgment about what he believes his patient would, or would not, like. The central figure is the patient. It is not I, the physician, who may be frustrated by the complexity and the persistence of the patient's problem and who may wish to resign from it. It is not the state, which might be anxious about the cost of medical care. It is not the relatives who may be overburdened by the constant awareness of a relative who might die. You can see the amount of bias any one of these parties will introduce. In this situation, then, the physician makes a decision that death is inevitable and imminent and, following discussion with the relatives, all support is withdrawn. The Natural Death Act does not alter this relationship between you and the patient. This conduct has always been that which we would expect.

The problems associated with the care, and the handling, of the dying patient unfortunately, I believe, go far beyond the confines of the Natural Death Act.

Is death inevitable? The definition and decision about inevitability of death is one which will come to different people at different times in the care of the patient, and the attitude I have is that there will come a time when it will become obvious to all the staff that death is inevitable. The bill states "if death is imminent, with or without supportive care." The problem with that is: What if death is not imminent with supportive care? It seems to me the problem is when life can be maintained, and death is not imminent in the face of your supportive care. It is an issue which is outside the confines of the present Act. Finally, presumably the Act is not to protect us, the physicians, against litigation. Such protection cannot be a motive for the Act, or we will be unprotected if the patient had not signed the directive.

In conclusion I would say that the Act will not end debate and doubt. It may in fact produce more doubt; it may in fact introduce interpretation, and misinterpretation, by lawyers and laymen, of each word and phrase. However, in the face of this, the great advantage of the Act is that it has opened this dialogue and from such dialogue it is to be hoped that satisfaction for patients, the relatives and the physician will be achieved.

DR. SADLER: *Thank you, Dr. Don. The audience may now direct its questions to the panel.*

QUESTION: *What is the responsibility of the hospital, or the physician, to bring the Act to the attention of a patient?*

ANSWER (Assemblyman Keene): I would suggest to you that there is probably an ethical duty and not a legal duty. The exact definition of that duty is one which would best be determined by a group, such as this, in their own discussion.

QUESTION: *Specifically with regard to the patient presented today, I do not understand the relevance of the Act. First, is this patient considered imminently dying? Second, is his expiration binding on the physician? Further, since the patient is*

*Hillary F. Don, MD, Associate Professor of Anesthesia, and Director, Intensive Care Unit, University of California, San Francisco.

required to sign a consent-for-surgery form to begin with, isn't the directive redundant in this situation, and is it in any way binding on anyone?

ANSWER (Dr. Sadler):—Would you accept that, when he re-enters the hospital for the revision of his shunt, and does not want it, and dialysis then is discontinued, death would be imminent and that dialysis does replace a vital function? What is binding is his directive for no more surgical procedures or life-support efforts.

QUESTIONER: *I think the signing of the directive, and the timing of that signing, would do nothing but confuse me. If I were in the emergency room when the patient came in, I would not know whether his doctors considered he was imminently dying. If he were imminently dying and since he signed the directive 14 days after the diagnosis (or more than that), would I be bound not to offer him surgical treatment under those circumstances? If it was clear he were imminently dying at the time of the decision, the legal ramifications of that are totally different than if he were not.*

ANSWER (Assemblyman Keene): I think you are confusing two states: that of the diagnosis of terminal illness and that of the imminence of death. With reference to the first, if the directive was signed at a time when the person was authorized as a qualified patient who is terminally ill by diagnoses of two physicians, the doctor is required to effectuate the document; but, the actual effectuation does not occur until death is imminent whether or not the life-support systems are utilized.

QUESTIONER: *I still do not understand whether he is legally, at the present time, imminently dying.*

ANSWER (Assemblyman Keene): Well, death may not yet be imminent but, as I understand it, it will be imminent somewhere down the line and, at that point, life-support systems are to be removed because the terminally ill patient will have decided he does not want them used if they serve no purpose except to postpone the moment of death.

QUESTIONER: *Which is the life-supporting system, the kidney machine or the access?*

ANSWER (Dr. Sadler): It would seem to me the shunt is part of the life-supporting system. It is simply a necessary artificial extension.

DR. SOLTER: I would just like to make one brief point. Mr. J's death is imminent when he no longer has vascular access and that is when the instructions are operative.

DR. SADLER: *Mr. J, do you understand what all this is about? They really wonder why you signed the Act.*

MR. J: Well, I am just going to tell you this. I have had 19 operations and I do not want to be cut open any more.

DR. SADLER: *The question would be, when that time came, why not just stay home and let nature take its course?*

MR. J: Makes no difference to me, whichever way they want it.

DR. SADLER: *However, if you are brought into the hospital, you want them to understand how you feel and carry out your wishes?*

MR. J: Right.

DR. SADLER: *Thank you.**

DR. LACKNER† (From the audience): It is known that I recommended to the Governor that this bill be vetoed. Let me explain my difference of opinion. I personally feel the legislation, although well-motivated, is ill-advised. I say this personally because Governor Brown disagrees with me about this. He feels that this is very good legislation. I also feel that there are certain things which are good about the legislation: first of all, it is good to establish that refusing treatment is not suicide, and that refusing treatment should not make it possible for insurance companies to decline to meet their commitments. I feel it is good to allow people to look toward some possible future state of incompetency and to make a determination which will help guide their therapy during that state of incompetency. Beyond these points, I have some very serious concerns.

I believe that all patients at all times, if they are competent and not under duress, have the right to decline all therapy. This goes for terminal patients and nonterminal patients. It goes for

*On February 1, Mr. J returned to the hospital for his dialysis with his shunt already clotted. Attempts to declot it were unsuccessful. He allayed the anxieties of the staff and reassured them that he fully understood the consequences of this medical problem and his directive that nothing further be done. He returned to his home but was readmitted in three days at the request of his family. Again he was dignified and stoical, again reassuring the staff not to worry, they had done all they could do. Three days later he died. Each member of the staff was deeply moved by his continuing dignity.

†Jerome Lackner, MD, Director, California State Department of Health, 1975-1978.

terminal patients whose death is imminent and terminal patients whose death is not imminent. It goes for terminal patients who have artificial, and mechanical, means of life support and it goes for those who have nonartificial and nonmechanical means of life support. Furthermore, I feel it is wrong to separate out dying patients from nondying patients. I think the emphasis should be on the right of all patients, at all times, to make decisions about their own care; that is, for them to be the primary decision-makers.

I do not believe someone should have to be a qualified patient before the Act applies. I do not believe you should make a distinction between those who have been certified within 14 days, and those who have not. Furthermore, I think it is wrong to make one single kind of form by which a patient can express this will. We can dispose of our property in many different ways and, yet, we can take care of this very important act in only one way.

My major fear about this bill is that if our colleagues are given one narrow exculpatory route from liability, then all of those people who do not fit into that narrow pattern will have a harder time to die. Most of us have not made wills regarding our property and most of us will not make wills regarding our termination. I am fearful that those of us who have not made wills regarding our termination will be assumed to have not wanted the physician and the family to make judgments about our termination in the event of our incompetence.

I want to point out, however, that I do not speak as the Director of the Department of Health of California; I speak just as a private, individual clinician. The Governor feels it is a good bill. I certainly respect Barry Keene. He is one of the finest health legislators in the state and perhaps in the nation, but I do strongly differ with him over this bill because I think it constricts severely the right to die. It creates more problems for those of us who are trying to help people when they are dying.

QUESTION: *I wonder if someone could expand a little bit on the provisions of the bill for those terminally ill patients who are considered to be of impaired judgment, perhaps for psychiatric reasons.*

ANSWER (Assemblyman Keene): There are a series of circumstances in which a patient would be incompetent and make certain demands upon the attending physician. I suppose that if the physician had reasons to suspect that the patient was incompetent at the time he prepared the directive, the physician ought not to effectuate the directive. He ought to operate under the law as it is now.

QUESTIONER: *However, it does not state the competency of the patient in the way the competency of a person who makes a will is stated in the will.*

ANSWER (Assemblyman Keene): If the patient becomes incompetent for whatever reason and if the patient was competent at the time he or she prepared the directive, it ought to be effectuated because those are exactly the situations for which the terminally ill patient wishes to prepare. The several situations with which the bill does deal are if the terminally ill patient is comatose; if the patient is incompetent; if the patient is not comaose but perhaps so severely sedated that he or she is considered to be incompetent, or if the patient is rational and the physician will not pay attention to the directive or the wishes of the patient. I have met several physicians who have told me that they will not effectuate these directives. Now, the standards of the profession may be different, the expectations with reference to those physicians may be different, but they will simply not listen to the terminally ill patient. They consider the patient, by virtue of his or her physical condition, to be in a kind of custodial state. That is what the bill deals with and that is what the bill is intended to deal with.

DR. SADLER: *We thank the panel for their comments; and, Mr. J, we are very grateful to you for attending this important meeting.*